

Listening to Caregivers: The Role of Needs Assessment in Program Planning

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EXECUTIVE SUMMARY

Washington state's Family Caregiver Support Program (FCSP), which was established in 2000, calls on Area Agencies on Aging (AAA) to develop services that meet the needs of caregivers in their regions. Like other state programs and the National Family Caregiver Support Program (NFCSP), Washington's initiative authorizes provision of a variety of services—information and assistance about long term care options, respite care, support groups, training and education, specialized transportation, and consultation with health care professionals. As part of its planning process for the FCSP, staff at Pierce County's AAA—Pierce County Aging and Long Term Care (PCALTC)—gathered information from caregivers in its community in an effort to design a program that would be responsive to their needs.

PCALTC's needs assessment consisted of two components: a survey questionnaire that was distributed to over 500 caregivers in Pierce County and a focus group that included caregivers and professionals who work with caregivers. In preparation for conducting the needs assessment, PCALTC staff consulted data from caregiver surveys as well as articles and books on the subject of caregiving, attended a national conference that featured sessions on caregiving, and followed the progress of local studies that focused on the availability and accessibility of information for caregivers. These activities helped inform staff about the nature of caregiving and provided a foundation for the agency's inquiry into the needs of caregivers in its community.

147 survey questionnaires were completed and returned for a 27 percent response rate and the results were revealing in several ways. Ninety percent of respondents rated a break from caregiving as either a "very important" (74 percent) or "important" (16 percent) need, but less than 50 percent of those surveyed had utilized respite services through PCALTC—a program for caregivers that existed prior to implementation of the FCSP. This suggested that efforts to educate the public about this service could be improved. Reinforcing this point was the fact that 89 percent of those surveyed indicated that easily accessible information about caregiver resources was either a "very important" (48 percent) or "important" (41 percent) need. In ranking their needs in this way, respondents also provided PCALTC staff with critical information for prioritizing a range of services that would be offered under the FCSP. Last, agency staff members were further enlightened by caregivers' written comments about the personal challenges they faced in their roles.

The focus group—which included four caregivers, a caregiver support group facilitator, and two staff members from an Alzheimer's/dementia caregiver support program—provided a forum for additional discussion of issues and themes that emerged from the survey results. In this setting, a number of ideas were generated for conducting outreach to caregivers, refining information and assistance services, and involving caregivers in FCSP planning and evaluation on a continuous basis.

PCALTC had a relatively short period of time to develop its FCSP plan. As such, it benefited greatly from cooperation and assistance it received from partners at the state and local level. These positive working relationships enabled the agency to further its efforts at assessing community needs as part of the program planning process. By listening to caregivers, PCALTC staff broadened its understanding of the educative role the agency could play in promoting

greater awareness of the nature of caregiving. Indeed, the needs assessment process offered a unique opportunity for PCALTC staff to consult with clients and potential clients in a substantive way by encouraging their participation in the development of the FCSP plan and bringing to light aspects of the inner world of caregiving.

INTRODUCTION

Washington state's Family Caregiver Support Program, authorized by legislation passed during the 2000 legislative session, calls on the state's 13 Area Agencies on Aging (AAA) to develop services for caregivers in their regions. Like other state programs and the National Family Caregiver Support Program (NFCSP), Washington's initiative provides for a variety of services—information and assistance about long term care options, respite care, support groups, training and education, specialized transportation, and consultation with health care professionals. Determining the levels at which these services would be offered, however, was a key task that each AAA undertook.

In its instructions for developing a Family Caregiver Support Program plan, the state's Aging and Adult Services Administration (AASA) posed the following questions to AAAs: What are the greatest unmet needs (i.e., service gaps) of caregivers in your area? What work have you done to determine these needs? How were the views of family caregivers considered? What will you do to respond to the needs of primary ethnic populations or specialized subpopulations in your area? These questions provided a useful framework for staff at Pierce County Aging and Long Term Care (PCALTC) in gathering information from caregivers about their circumstances and needs. Moreover, PCALTC's interest in conducting a needs assessment for this program was consistent with the approach it takes, and finds instructive, in drafting its Area Plan, which serves as a blueprint for the services it funds.

PCALTC's needs assessment consisted of two components: a survey that was distributed to over 500 caregivers in Pierce County and a focus group that included caregivers and professionals who work with caregivers. In preparation for conducting its needs assessment, PCALTC staff consulted data from caregiver surveys as well as articles and books on the subject of caregiving. In addition, PCALTC staff attended the National Home and Community Based Services Conference and participated in sessions on caregiving issues. PCALTC staff also followed the progress of two studies conducted by Bachelor of Science in Nursing (BSN) students at the University of Washington-Tacoma, which focused on the availability and accessibility of information for caregivers in the community. These activities helped inform staff about the nature of caregiving and provided a foundation for the agency's inquiry into the needs of local caregivers.

PCALTC received instructions for developing its program plan from AASA in early July 2000 and completed its plan in late September 2000. As noted below, PCALTC staff gathered general information about caregivers' needs prior to working on the plan, but most of its efforts to assess the needs of Pierce County caregivers were performed during a three-month period. It is important to note, however, that PCALTC requested and was granted an extension for submitting its plan, and this additional time allowed the agency to conduct its needs assessment.

GATHERING INFORMATION ABOUT CAREGIVERS' NEEDS

Prior to developing a survey questionnaire, PCALTC staff reviewed the growing body of literature on caregiving to deepen their understanding of relevant issues. Of particular interest were surveys that had been conducted by the Family Caregiver Alliance (FCA), National

Alliance for Caregiving (NAC), and AARP. These studies provided worthwhile insights into existing support programs, the challenges caregivers face, and the kinds of services that are useful in helping caregivers cope with their responsibilities. The FCA's "Survey of Fifteen States' Caregiver Support Programs," for example, provided an overview of different approaches to serving caregivers, key aspects of successful programs, and "best practice" models from several states. Addressing somewhat different issues, "Family Caregiving in the U.S.: Findings from a National Survey," published by the NAC and AARP, offered a useful perspective on the intensity of the caregiving experience as well as information on unmet needs as reported by caregivers (The National Alliance for Caregiving & The American Association of Retired Persons, 1997). PCALTC staff also broadened its knowledge base by consulting notable works by experts in the field of caregiving (Lustbader & Hooyman, 1994; Mace & Rabins, 1999; McLeod, 1999). Taken together, these resources and others provided important information about the content of caregiver surveys and myriad issues that affect caregivers.

PCALTC staff attended the 18th Annual Home and Community-Based Services Conference in Portland, Oregon in mid-September 2000 and this proved particularly beneficial to the agency's efforts to assess the needs of local caregivers. Although the conference was held after PCALTC conducted its survey of caregivers, it occurred before the focus group was convened and the final draft of the agency's plan was written. Hence, staff benefited greatly from participating in sessions, led by experts in the field, that explored caregiving issues and outlined models for assisting caregivers that have been developed in California, Wisconsin, Pennsylvania, and Oregon (Stone, 2000; Feinberg & Coleman, 2000; Browdie & McGuire, 2000; Bowers, 2000).

During the 1999 – 2000 academic year, two teams of BSN students at the University of Washington-Tacoma completed projects that addressed the availability and accessibility of information for caregivers in the community. Because caregivers' needs for information and assistance were a prominent concern, PCALTC staff took special interest in the studies' findings. Undertaken in conjunction with Tacoma's Young Women's Christian Association (YWCA), the student teams gathered data—compiled in separate reports—from social service agencies and caregivers to assess the need for a telephone resource line that would offer information and referral specifically for caregivers. The YWCA's interest in a caregiver "hotline" grew out of discussions that its staff had with a caregiver who, during the course of ministering to his ailing wife for seven years, observed that caregivers lacked a centralized information source where they could receive support and have their questions readily answered.

Although the numbers interviewed were small--eighteen caregivers and personnel from eleven social service and home care agencies--markedly different views about the availability and accessibility of information emerged. For the most part, social service agency staff felt that adequate information existed for caregivers and that it was accessible. A majority of caregivers, however, indicated that there was a lack of awareness about support services (Caudill, et al., 2000; Beauchamp, et al., 2000). Because of the disparate opinions expressed, PCALTC staff identified this as an area requiring further inquiry, surmising—based on these findings and knowledge of information and referral services in the community—that sufficient caregiver information existed but that it was not accessible at one location, and that social service personnel had not made concerted efforts to contact and educate those who could utilize this assistance.

Reviewing survey instruments and results along with selected literature on caregiving provided important information about caregivers' needs. These tools and the data they generated, along with impressions gleaned from accounts and analyses by and about caregivers, assisted PCALTC staff in their efforts to solicit input from local caregivers. Indeed, this research proved particularly useful as PCALTC staff designed its survey questionnaire and planned for convening a focus group.

LISTENING TO CAREGIVERS

PCALTC's decision to utilize a survey questionnaire and focus group to assess the needs of caregivers in its community was dictated in part by instructions it received from AASA, which clearly defined expectations in this area. Equally important, though, was the fact that PCALTC had previously employed both of these methods to successfully gather information from community members as part of its four-year planning process. Hence, PCALTC staff experience using these approaches was a key factor in their adoption.

A team of PCALTC staff members, which included an intern from the University of Washington-Tacoma's Master of Social Work (MSW) program, developed the survey questionnaire. The MSW intern wrote an initial draft of the instrument, after being fully briefed on the FCSP, participating in discussions about caregivers' needs, and becoming acquainted with agency and community resources. The team subsequently made revisions to the survey, adding several items and clarifying language where it seemed warranted. The questionnaire was designed to elicit information from caregivers about their needs, their participation in support groups, and their use of Respite—a state-funded program to provide unpaid caregivers with periodic breaks from their duties on a sliding fee scale basis that was established in 1989. It consisted of six questions, one of which asked respondents to rate fifteen types of assistance as either “very important,” “important,” or “not important” in their lives. Caregivers also were offered space to comment on needs that were not being met, and a substantial number took advantage of this opportunity to more fully explain their situations (See copy of questionnaire under Notes).

Questionnaires, accompanied by cover letters explaining PCALTC's interest in seeking input from caregivers, were distributed to 540 unpaid caregivers in August 2000. Many of these individuals were either on mailing lists for PCALTC's Respite program or an Alzheimer's/dementia caregiver support program in the county. In addition, surveys were disseminated to members of two small support groups that served those who care for victims of Alzheimer's disease and stroke. 147 surveys were completed and returned for a 27 percent response rate.

The results of PCALTC's survey were revealing in several ways. First, 90 percent of respondents rated a break from caregiving as either a “very important” (74 percent) or “important” (16 percent) need. Less than 50 percent of those surveyed, however, had utilized respite services through PCALTC, even though the average length of time they had cared for a loved one was just less than 7 years. Of those who volunteered why they had not used respite services, many claimed that they lacked information about the program, while others cited the expense involved or difficulties they had in arranging assistance at a suitable time. PCALTC staff members were somewhat surprised that more caregivers had not used its respite program,

given the fact that, as a group, they had been caring for family members or friends for a considerable period of time. Indeed, over 40 percent of those surveyed expressed interest in receiving information about Respite, reinforcing the idea that efforts to educate the public about this service could be strengthened.

Second, 89 percent of those surveyed indicated that easily accessible information about caregiver resources was either a “very important” (48 percent) or “important” (41 percent) need. In addition, they emphasized the necessity of obtaining help in applying for services and benefits, highlighting more generally, their need for assistance in negotiating the maze of programs and paperwork they often encounter. This prompted PCALTC staff to consider how the agency’s information and referral system could be more responsive to caregivers, which led to changes in program print materials, guided planning for educating the community about the FCSP, and informed decisions about receiving telephone calls from caregivers.

Third, in ranking their most pressing needs, respondents provided PCALTC staff with information that was valuable in prioritizing services that would be offered under the FCSP. Twenty-five (25) percent of the agency’s FCSP funds could be allocated for respite care, and based on the overwhelming percentage of those surveyed who cited this as a critical need, PCALTC devoted that amount to this service. Similarly, respondents’ interest in receiving advice from medical professionals and learning about disease and illness that afflicted their loved ones—needs that 83 percent and 77 percent of those surveyed rated as either “very important” or “important”—suggested to PCALTC staff that consultation with registered nurses, physical therapists, and dietitians should be an important component of the FCSP. Likewise, the fact that 76 percent of caregivers participating in the survey identified practical assistance such as bathing as either “very important” or “important”, pointed to the need for its inclusion in the menu of services to be developed.

Last, the remarks provided by respondents about their lives were profound. Few comments reflected any bitterness, but a number graphically portrayed the daily demands that respondents faced and the sense of isolation and powerlessness they sometimes felt. Some expressed gratitude for respite services and the support groups they participated in, while others voiced frustration at the lack of affordable assistance available to them. Still others took time to describe their circumstances—caring for two parents, tending to the needs of a parent and raising children, ministering to a spouse even though their own health was compromised—and these candid accounts impressed PCALTC staff, enriching considerably their understanding of the challenges that confront caregivers.

Issues and themes that emerged in the wake of the survey were explored further in a focus group that was convened in September. Participants included four caregivers, a caregiver support group facilitator, and two staff members from an Alzheimer’s/dementia caregiver support program. Participants responded to four lines of inquiry. First, we sought reaction to our draft plan and probed for further details as each person in the group commented. Second, we asked about problems locating caregiver support information, and how information and assistance services might be improved. Third, we asked the group for its suggestions about utilizing additional funding for the program should it become available (anticipating the NFCSP). Last, we queried group members about ways to involve caregivers in the development of the FCSP. The bulk of the group’s time, however, was spent soliciting ideas for enhancing

caregiver support services and this yielded a number of perceptive comments. Several participants, for example, highlighted the need for outreach to caregivers, so that they might avail themselves of services before crises occurred. They noted that caregivers are often preoccupied with their duties, may not identify with the role they have assumed, and may have scant knowledge about what a caregiver is. As a result, they are unaware of services that are available and fail to investigate resources that could provide support. Observations such as these encouraged PCALTC staff to examine the role it could play in educating the community about caregiving, a task that clearly exceeded supplying information about services.

Focus group members, like those who responded to the survey, also emphasized the need for a coordinated information system about a range of resources. Again, the experiences of these caregivers were instructive, in that all spoke of the confusion that accompanied their attempts to find assistance. At another level, though, they noted that it would be most helpful if those providing information and assistance through the FCSP had first-hand knowledge of caregiving. In essence, they argued that caregivers required something beyond guidance about where to turn for help when contacting information and referral staff. That something extra—understanding, compassion, empathy—could be best supplied by those who had cared for loved ones themselves. Although no guarantees on this score could be made by PCALTC staff, the importance of identifying exemplary personnel to work with caregivers was duly noted.

The question of how to involve caregivers, on an ongoing basis, in FCSP planning and evaluation was broached in the focus group and participants proposed creation of an advisory council composed of caregivers and interested professionals. Several focus group members expressed interest in being part of such a council, envisioning it as a means by which they could keep abreast of FCSP activities—through scheduled quarterly meetings—and make recommendations as needed. PCALTC staff recognized the value of this proposal and incorporated it into its plan for the program.

KEY CONSIDERATIONS AND PRACTICE IMPLICATIONS FOR THE AGING NETWORK

Program plans like the one formulated for the FCSP often need to be developed in a relatively short period of time, and PCALTC could not have accomplished its needs assessment had it not been given the time to do so. Hence, AASA's approval of the agency's request for an extension to gather information and perspectives from local caregivers was critical to the success of PCALTC's efforts. In addition, the work of the agency's MSW intern was vital. He not only prepared a first draft of the survey questionnaire and helped revise it, but also researched local caregiver support groups, assisted with the distribution of the questionnaire, and tabulated responses. In sum, PCALTC benefited greatly from its positive working relationships with AASA and the MSW program at the University of Washington-Tacoma. Indeed, these linkages enabled the agency to further its commitment to assessing community needs as part of the program planning process.

By listening to caregivers, PCALTC staff gained valuable insights into the educative role that the agency could play in the community—an issue that focus group members, in particular, helped to highlight. Beyond PCALTC's charge to inform caregivers and the broader public about the FCSP and its services lay the more daunting challenge of promoting a deeper

understanding of the nature of caregiving. Staff viewed this as the logical extension of PCALTC's responsibility, as an AAA, to provide information, assistance, and advocacy. Implicit in this task was the need to foster an open discussion of caregivers' needs so that a supportive network of community services and resources could be fashioned. Achieving that goal would require investigating possibilities for collaborating with partner agencies to sponsor educational forums, disseminate print material, utilize electronic media, and seek out those caregivers who remained isolated and hidden from view because of their socioeconomic circumstances, limited English-speaking ability, or other reasons.

In conducting its needs assessment, PCALTC staff connected with clients and potential clients in a substantive manner. The agency encouraged caregiver participation in the development of the FCSP by soliciting input from caregivers through the questionnaire and focus group—a key factor in successful program implementation. Moreover, the continued involvement of caregivers and those who work with them was ensured by identifying an advisory role they could fill once the program was established. Equally significant, though, PCALTC staff learned about the emotions associated with caregiving as people shared the satisfaction they felt in serving a loved one, the despondency they experienced when daily tasks overwhelmed them, and the anxiety that marked their lives as they sought to cope with numerous uncertainties. As important as it was for agency staff to know what caregivers needed in the way of services, it was crucial that they also attended to the inner world of caregiving. For an understanding of that realm meaningfully informs efforts to reach and serve those who care for others.

AUTHOR DESCRIPTION

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NOTES

Family Caregiver Support Project

Caregiver Survey Questionnaire

1. How long have you been a caregiver? ____ Yrs. ____ Mos.
2. Do you get breaks from your caregiving duties? Y N
If yes, how long and how frequent are these periods of respite? _____

Who provides these breaks? _____
3. If you do not receive relief from caregiving, what is the main reason for this?

4. Do you belong to a caregiver support group? Y N
If yes, what is the name of the group? _____
5. Caregivers need assistance in a number of areas. Please indicate how important the types of assistance listed below are to you.

1 = Very Important 2 = Important 3 = Not Important

____ a. Supportive individual counseling to help me cope.
____ b. Easily accessible information about caregiver resources (e.g., a central telephone “hotline”).
____ c. Guidance in legal matters (creating a living will, durable power of attorney, etc.).
____ d. Training to improve my skills as a caregiver.
____ e. Assistance in applying for services and benefits.
____ f. Information about the disability/illness that afflicts the person I care for.
____ g. Assistance with household chores (cleaning, cooking, laundry, shopping).
____ h. A support group where I can talk with other caregivers.
____ i. Advice from a medical professional (e.g., nurse, physical therapist, occupational therapist).
____ j. Financial guidance in planning for long-term illness.

- ___ k. A break from caregiving to use for personal business, relaxation, or recreation.
 - ___ l. Transportation for appointments and other essential trips.
 - ___ m. Special medical equipment for assistance with daily activities.
 - ___ n. Home modification to improve safety and/or access.
 - ___ o. Assistance providing personal care (e.g., bathing).
 - ___ p. Advice from a mental health professional about caring for my loved one.
6. As a caregiver, do you have needs that are not being met at present? Please use the space below to explain.

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